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**intelligence  
report ,**

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Senate Subcommittee Holds Hearing on Medicaid  
Financing of Services for DD Persons

Swift, decisive Congressional action is needed to ensure appropriate long term care services for Medicaid-eligible developmentally disabled persons, according to witnesses who testified at a September 19 hearing held by the Senate Finance Committee's Subcommittee on Health.

The purpose of the half-day oversight hearing on Title XIX financing of services for individuals with developmental disabilities was to explore relevant issues surrounding the eligibility and coverage of this subpopulation of Medicaid recipients. Witnesses were asked to focus their remarks on existing federal policy barriers to proper utilization of Medicaid funds on behalf of developmentally disabled recipients as well as proposed solutions, rather than on specific pieces of legislation. A total of twenty individuals, organized into five panels, presented oral testimony at the hearing. Senator David Durenberger (R-MN), Chairman of the Subcommittee, and Senator John Chafee were present throughout the hearing, while Senator George J. Mitchell (D-ME) and John Heinz (R-PA) attended briefly. In his opening remarks Senator Durenberger asked witnesses to focus on the question of how federal programs can assure that people with developmental disabilities receive appropriate services in a manner that ensures their safety, development and well being. The Subcommittee, he said, was aware that the issues involved were complicated and emotionally charged, especially the "trade-offs between institutional and community based care." Senator Chafee asked witnesses to focus on the question: "what does the future hold if there are no changes to the Medicaid program?" He added that "the Medicaid program is in basic need of reform; such reform should be based on the premise of a range of services which are available to developmentally disabled individuals based on their unique needs."

Senator Weicker's Testimony. Senator Lowell Weicker (R-CT) was the first witness to testify. He began by discussing the differences between two statutes enacted by Congress in the 1970's - P.L. 94-142, the Education for All Handicapped Children Act and Section 1905(d) of the Social Security Act, authorizing ICF/MR benefits. The purpose of P.L. 94-142, he said, is to guarantee a free, appropriate education to all handicapped children; therefore, each student is assessed and provided only

the services he or she needs. By contrast, under the ICF/MR program all services are furnished to everyone enrolled in the program, so recipients have access to a lot of services that they don't really need. The ICF/MR program, Weicker noted, also has an institutional bias and too often provides limited custodial care to clients who could benefit from developmentally oriented services.

Alluding to the shocking findings of hearings on institutional abuse and neglect which he chaired last year, Senator Weicker said that "we have failed to meet President Kennedy's goal" of decreased reliance on institutions and increased services in the community. Although we have made some progress (e.g., passage of the Mental Health Protection and Advocacy Bill in 1986), we now need a totally different approach to serving developmentally disabled people in the community, which does not ignore or neglect families who have kept their disabled children at home, rather than place them in institutions. "Our goal should be, to mainstream all developmentally disabled people," Weicker remarked. There is no disagreement on the state-of-the-art. "The way to go is the community," but in doing so, "society should not penalize those that made the decision to institutionalize..." their children years ago, he added. Senator Durenberger agreed, saying "we have to turn the Social Security Act on its head and look at it in terms of 1986."

Administration Panel. The next panel consisted of two witnesses from the Department of Health and Human Services - Glen Hackbarth, Deputy Administrator of the Health Care Financing Administration and Carolyn Gray, Deputy Assistant Secretary of Human Development Services.

Mr. Hackbarth pointed out that when the ICF/MR program was launched in 1974 most participating facilities were large public institutions. However, today only 25 percent of all certified ICF/MR facilities are public facilities, while private facilities comprise 75 percent of the program and serve some 46,000 persons. He also noted that 35 states operate approved Medicaid home and community care waiver programs for persons with developmental disabilities.

Mr. Hackbarth also discussed HCFA's efforts to aggressively enforce federal ICF/MR regulations. This year (FY 1986), he said, "we have conducted 514 look behind surveys and 80 facilities have been notified of adverse actions." He added that HCFA is in the process of revising ICF/MR standards (see Intelligence Report bulletin No. 86-15, dated March 6, 1986) in order to focus more attention on the provision of active treatment and the impact of such services on residents of the facility.

Ms. Gray focused her remarks on the activities of the Administration for Developmental Disabilities. She mentioned that an estimated 87,000 developmentally disabled workers have been employed in private sector jobs as a result of ADD's employment initiative. She also said OHDS is committed to promoting full participation in society by those with disabilities, adding that "we look forward to a time... when hire-ability is not limited by disability."

Subcommittee members asked Mr. Hackbarth several questions. First, Senator Chafee asked when final regulations governing ICF/MR reduction plans, as authorized under Section 9516 of P.L. 99-272 (COBRA), would be released. Mr. Hackbarth said HCFA has no intent to prematurely close large ICF/MR facilities without assurance that adequate care alternatives are available to residents. "That would be irresponsible," he said. Regulations governing Section 9516 correction plans, he reported, will be finalized in the late fall of 1986.

Senator Chafee pointed out that the Section 9516 makes it clear that it is effective upon enactment; why then, he asked, were officials in Colorado and Hawaii told they could not utilize the phase-down provision until after HHS/HCFA regulations are finalized. Mr. Hackbarth said that somewhere in P.L. 99-272, "I think it was in the report language," is a statement indicating that the regulations would have to be finalized before reduction plans could be approved. Besides, retroactive implementation of this provision would lead to administrative chaos. In addition, in the case of the same two states Senator Chafee asked about HCFA's plans with regard to applying Section 9516 to facilities notified of deficiencies prior to issuance of final Departmental regulations. Obviously dissatisfied with Mr. Hackbarth's response, Mr. Chafee said he would be pursuing the matter further with HHS officials.

"What are you doing to implement the Secretary of HHS's goal of increasing community living options?" Senator Chafee asked. Hackbarth said the HCBC waiver program was HCFA's primary vehicle for encouraging states to develop community-based alternatives. The Senator pointed out that the waiver authority is tenuous and imposes all kinds of restrictions on the states. Mr. Hackbarth responded that HCFA was merely carrying out the will of Congress in limiting waiver services to clients who otherwise would require care in an ICF/MR facility at equal or greater cost to the Medicaid program. "How many clients receive waiver services," Chafee asked. Mr. Hackbarth said 61,000 compared to 146,000 in ICF/MRs. [N.B., This answer creates a false impression, since only 22,000 of the 61,000 are developmentally disabled clients.]

Next, Senator Heinz engaged in a terse exchange with Mr. Hackbarth regarding state incentives to minimize ICF/MR costs. "Doesn't the federal government pay about half the cost of Medicaid," he inquired. Hackbarth said yes. "My question is," continued Heinz, "if the states also pay half, aren't they in the same boat? Don't they have the same incentives to contain Medicaid costs?" Mr. Hackbarth said that the incentives were not the same, since the federal match was higher than 50 percent in many states. Heinz pressed him until he established that while the federal match was as high as 78 percent in some states, the national average was 56 percent federal, 44 percent state.

Research Panel. Charlie Lakin of the University of Minnesota, Center for Residential and Community Services was the first witness on the research panel. The ICF/MR program has taught us that there is no one perfect model of care," he told the subcommittee. Citing statistics gathered by the Center on the ICF/MR program in 1977 and 1982, Lakin said his conclusion is that "there is no justification for a long term commitment to segregated, institutional services; we need community integration." He added that states vary remarkably in the size and dynamics of their ICF/MR programs, and more equity is needed across states. He stressed that Medicaid funds are gradually being shifted from large institutions to small, community based ICF/MR and waiver supported residences, adding there should be a national policy on the delivery of quality services to mentally retarded people in the most integrated setting.

David Braddock of the University of Illinois at Chicago, | referring to Mr. Hackbarth's response to Senator Heinz, said he was distraught by the degree to which HCFA is unaware of statistics related to the Medicaid program as it impacts on developmentally disabled recipients. As of June 30, 1986, he indicated there were 100,412 developmentally disabled people residing in state-operated institutions. In the last three years, he added, the proportion of Medicaid funding devoted to large state institutions has plateaued at 75 percent; if non-state operated ICF/MR facilities with more than 50 beds are taken into account, the percentage devoted to large facilities rises to 87 percent. "Although a number of states have made great strides in developing small, community-based facilities, most are struggling and we now require national leadership [to move the states] in the direction of community services," he stated.

Braddock pointed out that fifteen years ago the federal government made a commitment to reform institutions, but "we are just as far from [that goal] now as we were then. We need a substantial readjustment of the [ICF/MR] program." He suggested that a simple adjustment in the federal Medicaid matching ratio, providing states with five percent higher match for community-based

services and a five percent lower match for institutional services, would send a clear signal of federal direction. "It is time for HCFA to catch up with [policy goals articulated in] the Disabilities Act," he concluded.

James Conroy of the Developmental disabilities Center at Temple University discussed the findings of the Pennhurst Longitudinal Study, a five year effort to determine the policy implications, costs and human impacts of the court-ordered deinstitutionalization of Pennhurst Center a state-operated residential facility in Southeastern Pennsylvania. He summarized the study's conclusion by saying that former Pennhurst residents were "much better off," in all of the dimensions measured, after they were placed in integrated community settings; they gained skills, and, although 70 percent of the families were initially opposed to their relatives moving to the community, after the move, over 90 percent were pleased with the results. He added there was a lower total "social cost" (all public dollars spent), but the primary reason was the difference in staff salary scales of state employees and employees of private vendor agencies. He recommended the formulation of a clear and coherent federal fiscal policy aimed at promoting the continuation of the trend towards small, community-based programs.

David Mank, Assistant Professor of Special Education and Rehabilitation at the University of Oregon, indicated that "supported employment is the most appropriate day service." Throughout his testimony, Dr. Mank said that the Medicaid program is rife with disincentives to the provision of meaningful, employment-related day programs. He added that there should be a federal policy addressing these disincentives and offering states incentives to develop integrated community services.

In response to a question from Senator Chafee, Mr. Braddock stated that the problem with the ICF/MR program is its "medicalization." The ICF/MR program "...may have to be extricated from Medicaid," he said "with specific federal and state agencies responsible for [the delivery of long term care] services to this population."

Mr. Chafee stressed that the basic thrust of his proposed bill, the Community and Family Living Amendments (S. 873), is "way beyond costs," but, nonetheless, he asked Dr. Conroy to explain why community costs are generally lower than the cost of institutional services. Conroy indicated that personnel costs are the primary cost of any care, and if these expenses were equated, he would expect little difference between the cost of community and institutional services. He reported that in the beginning of the Pennhurst study state institutional employees were receiving an average salary of \$14,000 plus a benefits package valued at 40

percent of their salary, while community direct care workers, performing similar tasks earned an average of \$9,600, plus 21 percent in fringe benefits.

State Officials. The next panel consisted of a State Medicaid Director and three state directors of mental retardation/developmental disabilities programs.

Barbara Matula, Director of the North Carolina Medicaid Agency, spoke on behalf of State Medicaid Directors' Association. She noted that the quality of care in large ICF/MR facilities has improved, but costs are now as high as \$40,000 per client per year. She contrasted these costs with the cost of services under North Carolina's HCB waiver program for the developmentally disabled, which range from \$12,000 to \$19,000 annually. She discussed the fact that the number of recipients a state is allowed to serve under a Section 2176 waiver is tied to the number of actual or projected vacant ICF/MR beds in the state, which creates a disincentive for states to phase down large facilities. As an example North Carolina serves 3,000 residents in ICF/MR facilities, but can justify serving only 300 in its DD waiver program. She pointed out that parents have little financial incentive to keep their handicapped children at home since parental income is "deemed" available to the child while he or she is living at home; consequently, only children in very poor families can qualify for Medicaid benefits. However, if the child enters an institution, parental income is no longer taken into account in determining his/her eligibility.

She said that as more severely handicapped clients are moved out of large facilities, "we will lose the economies of scale," it costs approximately the same to serve clients in the community as in state institutions. She concluded that "we need ICF/MRs, but with 300 waiver slots and 3,000 ICF/MR beds, the imbalance [in federal policy] is clear and we must address [this problem]."

Ben Censoni, Deputy Director of the Bureau of Community Residential Services, Program Development, Policy and Standards in the Michigan Department of Mental Health and Chairman of NASMRPD's Governmental Affairs Committee, spoke on behalf of the Association. He outlined four steps that were required to reform Medicaid policy as it applies to developmentally disabled recipients. First, the institutional bias of the ICF/MR program would have to be eliminated. Second, disincentives to moving DD people into the community would have to be removed by establishing a firmer basis for funding community-based services than the existing HCBC waiver program. Third, the current "dependency building" orientation of Medicaid long term care policy would have to be reversed. [N.B. He offered the example of Medicaid-reimbursable clinic services in Michigan, saying that

converting existing non-vocational day services to supported employment programs would be highly appropriate for many clients, but state costs would increase sharply due to the resultant loss of federal Medicaid dollars]. Finally, the assumption that recipients must require 24 hour care in a facility-based program in order to qualify for Medicaid long term care services must be modified. As a solution, Mr. Censoni suggested that states be offered the option of amending their state Medicaid plans to cover a wide range of community-based services, rather than having to dependent on Secretarial waivers to provide services in the community. A state plan option would build incentives for community-based services and permit states to tailor services to the individualized needs of eligible recipients.

Mr. James Towes, of the Oregon DD program office, said that his state maintains a policy that all persons with developmental disabilities should live, work and recreate in family, neighborhood and community settings. However, he added that Oregon has a "long way to go" to meet this policy goal and state officials are frequently frustrated in their efforts to expand community alternatives by federal policies which reinforce institutions. The examples he cited included: (a) several families of institutionalized children in Oregon that have agreed to take their children home if the state could provide one day per week of respite care; the HCFA regional office, however, has advised state officials that reimbursement can be claimed for only 30 days of respite care per annum under the state's HCBC waiver program. As a result even though the overall cost to the Medicaid program would be reduced by two-thirds, these children remain in an ICF/MR facility today; (b) federal ICF/MR "look behind" surveys are requiring states to make increased resource commitments to upgrade institutions, which detracts from the state's ability to expand community-based service options; and (c) all ICF/MR beneficiaries do not need the full panoply of services mandated under federal regulations although the state is required to assure that such services are available to all residents, even though the result is increased program costs with little or no benefits for the residents of such facilities. He concluded that the present "institutional bias" of Medicaid policy must be removed and suggested that states be given broad flexibility in designing and funding community services in exchange for a federal cap of long term care funding of services to the DD population, indexed to future population growth and cost of living adjustments.

Edward Skarnulis, Director of the Minnesota Division for Mental Retardation Services, noted that Minnesota has one-eighth of all the ICF/MR facilities in the nation. His primary recommendations centered on allowing states more flexibility to achieve their programmatic goals. Like Mr. Censoni, he criticized the Medicaid

disincentives to offering clients employment-related day services.

Senator Chafee told the panel members that if they wanted to provide services in the community, HHS's answer would be "we'll give you a waiver;" "so what is the problem," he asked. Ms. Matula said "you shouldn't hold your breath waiting. It takes the patience of a saint to qualify for waiver services."

Facility Employees. The next panel consisted of an institutional superintendent, a director of a private residential program and a union leader. Richard Scheerenberger, past president of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, said that over the years, he has had several basic concerns regarding the use of Title XIX as a funding source for MR/DD programs. Title XIX has significantly assisted states in improving services to institutional residents, most of whom are severely handicapped adults; but, it also has notable pitfalls. "Since 1974," he told the Subcommittee, "50 percent of individuals discharged from institutions have been moved to another institution -- usually a nursing home. We are playing musical institutions." He recommended that if federal policy is modified to focus more attention on community-based services, such services should not be funded through Title XIX. "The handwriting is on the wall for large institutions," he added, "since 80 percent of their residents are adults," but that does not justify eliminating the hard-earned improvements in the quality of these facilities in our rush to substitute community alternatives. "If we are going to do it [i.e. develop community alternatives], then for heavens sakes let's do it right," he concluded.

Bonnie Jean Brooks, representing Opportunity Housing (a private provider agency in Maine) spoke next, representing the National Association of Private Residential Facilities for the Mentally Retarded. Through a series of vignettes about former institutional residents who have made extraordinary progress in community-based settings, Ms. Brooks made the point that the shift of Medicaid funded programs to the community has been a success; without it, she said, people would still be living in "dehumanizing" institutions. She also cited a "growing body of evidence" that community services are more cost-effective, despite differences in reimbursement rates for public and private facilities.

Peter Benner, Executive Director of Council 6 of the American Federation of State, County and Municipal Employees (AFSCME), pointed out that AFSCME currently represents over 100,000 state institutional workers nationwide. He recommended that: (a) the



ICF/MR regulations be revised to eliminate arbitrary requirements; (b) alternatives to institutional care be obligated to meet quality standards and employ workers with skills and experience; and (c) all concerned parties must be involved in determining the path toward the future. He said institutional closures are "difficult and tense, when there are losers." Our union members have been seen as part of the problem over the last ten years," he added. In fact, he noted, AFSCME's primary concern is that high quality services continue to be provided to clients.

Senator Chafee noted that in Rhode Island, the state has been able to successfully reduce its institutional population due in large part to the good relationship between state managers and the local AFSCME affiliate.

He also asked Ms. Brooks whether a permanent waiver authority would address some problems of the ICF/MR program. She said it would cut down on the time and energy required for renewals which detracts from a state's ability to serve clients. In response to a question from Senator Mitchell she added, "I personally don't think there is a role for institutions [in the future.]"

Other National Organizations. Ruth Luckasson, representing the American Association on Mental Deficiency, expressed concern about the large numbers of handicapped students graduating from special education programs without any assurance of access to appropriate adult services. "We can't let them down by offering an outdated residential service system" she said. AAMD supports HCFA's efforts to revise ICF/MR regulations because of the need for improved client-centered monitoring of such facilities.

Colleen Wieck, representing the Minnesota Governor's Planning Council on Developmental Disabilities and the National Association of Developmental Disabilities Councils, made four points. First, billions of dollars are being spent on ICF/MR services nationally, but the outcomes may be "retarding environments and inactive treatment." The positive impact of community care has been documented, she noted.

Second, Medicaid is a powerful incentive for out-of-home placements, while family support programs are the lowest priority for funding. The waiver is an excellent beginning, but it needs to be expanded.

Third, restructuring Medicaid means dealing with "tough issues, inevitable choices and political heat," she indicated. States must determine what will be done with old buildings, how to deal with institutional employees and how to address the issue of

funding a bifurcated system. Finally, she said that restructuring Medicaid means "catching the new waves and funding what is needed and what is possible." Among the new waves she cited were supported employment and offering people with developmental disabilities the option of choosing their living environments.

In response to a question from Senator Durenberger regarding quality control, Dr. Wieck said it was vital to look at program outcomes, and she believed that adequate instrumentation could be developed to accomplish this task.

Advocates Panel. The final panel consisted of representatives from four advocacy organizations. The first witness was Jeff Gunderson, a former resident of a Medicaid-funded nursing home who now lives in a HUD-subsidized apartment, speaking on behalf of United Cerebral Palsy Associations, Inc. He said living in the community is difficult at times, but it is nothing compared to living in a nursing home. "They treat you like an animal [in the nursing home]," he told the Subcommittee. "There is not a prayer for people who are stuck in nursing homes because of state funding," he added, referring to the "institutional bias" of current Medicaid policy. "It is not fair for people who cannot advocate for themselves."

Dee Everitt, representing the Association of Retarded Citizens of the United States, said "Medicaid does not work for people who can't get it. We applaud Congress for passing the ICF/MR legislation, but the goals of the program [are now out of] step with the state-of-the-art in services." She described her severely handicapped daughter who has never lived in an institution, and said she hopes she never will. She presented four principles that the Finance Committee should keep in mind as it considers reforming Medicaid policy: (a) federal policy should support community and family-based services; (b) there should be decreased reliance of large facilities; (c) reform measures should recognize the long term effectiveness of home and community-based services; and (d) reform measures should remove the "institutional bias" and offer states increased flexibility.

Patricia Crawford of the Mental Retardation Association of Nebraska, also described the service needs of her daughter, a severely handicapped resident of a large public ICF/MR in Nebraska. "HCFA is imposing active treatment standards on these fragile people," she said. "Many people think fifteen hours a day [of active treatment] is too much for them. It is another rock being thrown at institutions, whose residents have a very faint voice. They need our help and national attention more than drug addicts do."

The last witness was Dana Kruse, representing an organization of parents of chronically ill children, called Sick Kids Need

Involved People (SKIP). She also described her own daughter, who as a result of a near drowning incident suffered multiple disabilities and became comatose. She pointed out an inherent contradiction in current policy that allows a state to pay for institutional care, even though the family may prefer to have their child at home and it would cost the government considerably less. She also criticized the heartlessness of forcing parents to "spend down to the poverty level" in order to qualify their child for non-institutional Medicaid benefits.

Next Steps. At the close of the hearing, Senator Durenberger stated that "long term care is on the Committee's blackboard of the coming year, and you will see us coming to grips with the challenge that John Chafee has put before us [to improve services to developmentally disabled persons and remove the "institutional bias" of the Medicaid program]." Mr. Chafee concluded that those present should "bear in mind that we are not just talking about institutions versus community living, but about human beings; we must remember this as we wrestle with the issues before us."

No follow-up activities to this hearing are expected during the remainder of the current session of this Congress, which is scheduled to end on October 3. Senator Durenberger's closing comments suggest that the prospects of Congressional action next year on issues discussed during the hearing may be somewhat better than they have been in past years. Many problems need to be resolved, however, before a viable reform bill can be developed.

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